

ANNEX VII 3: LITHUANIAN REPORT

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1. What definitions of Intellectual Disability are typically used in your Member State? Is there an ‘official’ definition?

According to the current Lithuanian legislation, concerning the definition of "disability", different terms of general nature are used in different legal acts: "invalidity", which refers to the loss of the capability to work; "persons with disabilities" "person with mental disabilities"; for educational purposes, "person with special education needs". The term "intellectual disabilities" is not precisely defined in the laws of the Republic of Lithuania.

The Law on Mental Healthcare 1995 specifically focuses on the area of mental health and mental patients. It uses such terms as: "mental (psychiatric) patient (patient)" which is perceived as the person, who has psychiatric illness; and the "patient" who is understood as the psychiatric patients or any other person, who makes use of mental health care.

Disabled person (invalid) is a person who due to inborn or acquired physical or mental disorders can neither fully take care his/her personal and social life nor implement his/her rights, nor accomplish his/her duties (by order No.226/49 of April 2000 issued by Minister of Health and Minister of Social Security and Labour of the Republic of Lithuania).

2. What is the historical context in which services have developed in your Member State?

Since the beginning of its establishment as a public organisation in 1989, *Lithuanian Welfare Society for People With Intellectual Disability “Viltis”* (in English “Hope”) started raising an issue of reintegrating individuals with developmental problems into society. Since then, the organisation became an initiator and promoter of forward reforms. Traditionally child mental health services were provided in large institutions (psychiatric hospitals and orphanages). Many psychiatrists were trained according to biological model of so-called Moscow school, which assumed that autism is a form of childhood schizophrenia. Therefore biological model of care prevailed.

In 1990, political, economic and social changes in Lithuania introduced the possibility to develop for the first time in nations' history an effective and modern system of child mental health services. During the period between 1990 and 1995 a new model of services was developed in the Department of Social pediatrics and child psychiatry of Vilnius University. The model included development of child and adolescent psychiatric services, as well as early intervention services for infants and preschool children with developmental disabilities. The emphasis, following recommendations of WHO and existing international standards, was made on deinstitutionalization and development of family-oriented and community-based services, which have been ignored by previous system. In the first half of 90's of 20th century, new training programs for professionals were introduced, more than 50 methods of assessment,

treatment and rehabilitation, new for Lithuanian clinical practice, were implemented, and a new model of services, including primary, secondary and tertiary level of prevention, was introduced in demonstration sites.

3. Are specific legal rights afforded to people with intellectual disability?

Education, disability specific service provision, etc. Situations where rights may be revoked on the basis of incapacity?

3.1. Procedures for assessment of person's disability and special needs.

There are different procedures used in the assessment of children with disabilities, for educational, social care purposes; and in the assessment of adults with disabilities, for disability status and access to social benefits. Until recently the Law on Social Integration of People with Disabilities 1991 established the functioning system of determining disability. The Law regulated the assessment of disability, medical, vocational and social rehabilitation for disabled persons, the adjustment of conditions for the disabled, as well as the development and education of the disabled. It established legal, economic and organizational guarantees for the occupational, vocational and social rehabilitation of the disabled. The disability assessment procedures for adults (age 18 and over) established an individual's disability according to one of three disability groups, I, II or III. Indicated group of disability provided the right to receive state social insurance and other pensions, benefits, privileges.

The "new Law on Social Integration 2004 aims to change the concept of, and attitude towards, people with disabilities in Lithuania. In particular, the Law on Social Integration 2004 directly establishes the principles of equal rights and equal opportunities for people with disabilities, as well as their protection from discrimination and exploitation. Outdated terminology, such as "invalidity" or "handicap", are changed to internationally accepted terms such as "people with disabilities" or "people with special needs". The law will also lead to significant changes in disability assessment procedures for employment purposes and access to social benefits". According to the Law on social integration 2004 instead of disability group individual's working capacity (graded in percentage) will be established, when the person is considered as having no working capacity (0-25 percent of working capacity), having partial working capacity (30-55 percent) and full working capacity (60-100 percent). Unlike the previous practice the working capacity will be established for people from age 18 until old age. Besides the special needs may be established and provided for persons who due to the inborn or acquired long term health conditions (disability or loss of working capacity) and unfavorable environment factors are in the urge of such special support. Special needs, established and provided for persons, disregard their age, level of disability or working capacity, may be the following: the special need of constant nursing, the special need of constant care (support), etc. However, entering into force from 1 July 2005 this new legislation base will only start functioning and forming new disability evaluation practices, it is difficult yet to evaluate its effectiveness and benefits towards people with disabilities.

3.2. Situations where rights may be revoked on the basis of incapacity?

Lithuania has created a strong legislative basis for the protection of the rights of people with disabilities, and this foundation has been further strengthened in recent years, in particular through the transposition into national legislation of the EU Employment and Race Equality Directives. Despite these positive changes, the lack of comprehensive

and consistent data on people with disabilities, across all relevant sectors, makes it difficult to assess the real situation of people with intellectual disabilities in Lithuania, so that it is hard to translate the solid legislative base into effective policy. Hence, although the 2001 population census did include for the first time questions on disability, data on people with intellectual disabilities is subsumed within the broader category of people with mental disabilities. This makes it very difficult to identify the specific problems faced by people with intellectual disabilities. It is important, therefore, that the Government establish an effective system for the comprehensive and regular collection of data on people with disabilities, so that the data is disaggregated by type of disability, including intellectual disability.

Adults and children with disabilities face a number of different assessments throughout their life. Available data indicates that most adults with intellectual disabilities are assessed as having a more severe level of disability, either disability group I or II, which has some important consequences. One of these is that most people with intellectual disabilities are declared legally incapable by the courts at age 18. They are placed under guardianship and lose all their civil and economic rights, including the right to work. This loss represents an important barrier, not only to their access to employment but also to their social integration. Although curatorship, under which the civil capacity of a person is limited, rather than fully removed, does exist in Lithuania, it is not permitted in the case of people with intellectual disabilities. To encourage the fuller social inclusion of people with disabilities, the Government should, as a priority, look into ways in which people with intellectual disabilities could, on an individual basis, exercise their rights to the fullest possible extent, according to their abilities. As a first step, existing legislation should be amended to also permit the limitation of civil capacity for people with intellectual disabilities, as an alternative to declaring them fully legally incapable.

3.3. Education, disability specific service provision, etc.

Access to education

Over recent years, there have been several encouraging developments concerning access to education by children and young people with intellectual disabilities in Lithuania. This is evidenced by the significant increase in the number of children with intellectual disabilities who are fully integrated into mainstream schools. The Law on Special Education 1998 established the basis for the inclusive education of children with intellectual disabilities, and the legislative basis for special education has since been strengthened through amendments to the Law on Education. However, although the Law on Special Education is both progressive and innovative, the very fact of maintaining a separate law on special education serves only to reinforce the perception that children with special needs, including children with intellectual disabilities, are "different". In this way, the separate law indirectly increases the stigmatisation of children with intellectual disabilities. It would send a strong message of support for inclusive education if the Government would prepare a united legal act on education in Lithuania, by bringing all the provisions on special education and education together under a common legislative basis.

Government policy on education is also progressive. The ongoing reform of the education system, in line with "National Educational Strategy for 2003-2012", will benefit children and young people with intellectual disabilities and improve the funding of special education. However, many important measures, in particular the introduction

of the new system of education financing, have not yet been fully implemented. Lack of adequate funding at the municipal level has been one problem. Another is that necessary secondary legislation has either not yet been created or has not been implemented. To ensure that this reform process moves ahead as swiftly as possible, the Ministry of Education and Science should make it a priority to see that all necessary secondary legislation is drafted and implemented. In addition, the ministry should regularly review progress on its overall policy on the integration of children and young people with disabilities into mainstream schools, to ensure the successful translation of policy into improved educational opportunities for children with intellectual disabilities.

The general problem of lack of specific data on people with intellectual disabilities is also apparent when assessing their access to education. Although detailed statistics are available on the number of children with intellectual disabilities attending mainstream schools, these are not yet available in the case of children who either do not receive any education at all or who receive home schooling. It is important that the Ministry of Education and Science monitor closely the situation of children with intellectual disabilities who are outside of the education system. To this end, the ministry should as a first step, seek to improve the collection of data on children receiving home education, or no education at all, as the basis for encouraging their entry into the education system. For those children for whom home schooling is the best available option, in particular, in cases where it enables children to remain with their families rather than being placed in a special boarding school, the ministry should monitor the quality of education these children receive in practice.

The comprehensive system of early intervention, or "early rehabilitation", services in Lithuania has already produced good results. Yet many children with intellectual disabilities, in particular those with more severe disabilities living in smaller towns and villages, are still not able to attend a kindergarten. For integration to be effective, it is important that it occurs at a young age. The Ministry of Education and Science should therefore undertake a review, to seek ways to improve the access to mainstream pre-school education for children with intellectual disabilities. At the same time, the ministry should also review the education of children with intellectual disabilities in special boarding schools. Wherever possible, children in these schools should have the chance to attend a mainstream school.

Parents, teachers, education specialists and NGOs have all played an important role in the successful integration of increasing numbers of children with intellectual disabilities into mainstream schools. However, although parents of children with intellectual disabilities have the right to choose which school they wish their child to attend, in practice, their choice is often limited by the availability of social and education services. To further strengthen the integration process, there still remain a number of areas on which the Government and the Ministry of Education and Science should focus. First, the qualification and training of all teachers working with children with intellectual disabilities should be improved. Second, support to children with intellectual disabilities, including special pedagogical and psychological assistance, compensation technology and special learning measures, should be made more readily available. Third, municipalities should be provided with sufficient funding to ensure the transportation to school of children with intellectual disabilities, especially in rural areas and in winter.

4. What is the estimated prevalence figure for intellectual disability in your Member State ? Both in term of an estimated 1-3% of the population who have an IQ is less than 70, and in terms of known service users. Is there any published material on prevalence studies?

A study, which assessed 6018 school children in 14 randomly selected secondary schools, was carried out in Vilnius. It aimed to establish prevalence figures for Asperger syndrome (AS) and childhood autism (CA). It has shown that minimum prevalence of AS is 4,3 per 1.000 children and male : female ratio of 1,9:1. A total prevalence of CA is 11,8 per 10.000 was found, being 15,1 per 10.000 in boys and 8,4 per 10.000 in girls. The boy : girl ratio was 1,9:1. The degree of autism, as assessed by CARS, was mild to moderate (scores ranging from 30 to 36,5) in 38 (39,2%) of the cases, and severe (scores ranging from 37 to 60) in 59 (60,8%). 74,5% of girls and 53,1% of boys had severe autism ($p=0,033$). Borderline IQ or mild mental retardation was seen in 23 (22,7%) of the cases, moderate in 42 (43,3%), severe and profound in 32 (33,0%). There was significant relationship between the degree of autism and level of mental retardation ($p=0,000$). Epilepsy was found in 38 (39,2%) of cases and was related with the degree of autism and mental retardation. In 23 (21,7%) of the cases co-occurring medical conditions associated with autism were diagnosed; they ranged from chromosomal to neurocutaneous disorders and metabolic and infectious diseases. (Source: Lesinskiene S. (2000) Autistic disorder among children of Vilnius).

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According to Lithuanian Health Information Centre, in 2005 the number of first time diagnosed mental retardation is 542 persons (15.9 / 100.000 population); number of adolescents and adults (14 years of age and older) is 270 (9.5 / 100.000 population), and number of children under 15 years of age is 272 (46.5 / 100.000 population). Total number of morbidity with mental retardation in 2005 is 18730 persons (550.4 / 100.000 population). Morbidity of adolescents and adults (14 years of age and older) is 15980 (562,6 / 100.000 population), and among children 2750 (470.0 / 100.000 population).

National Mental Health Centre has some data about disability related to mental disorders (www.vpsc.lt), however these data contain total number of people with intellectual disabilities e.g. in 2004 there were 9089 persons with intellectual disability, indicating cumulated data after social disability assessment for social benefit system).

5. What databases/sources are available in your Member State that might provide information on prevalence? Medical or social benefits, disability databases etc.

There is a database in Lithuanian Health Information Centre (Lietuvos Sveikatos informacijos centras; <http://www.lsic.lt>) about health care indicators. However the information for monitoring of healthcare indicators is lacking essential data on disability prevalence, burden and need indicators. So-called prevalence and morbidity figures are based on healthcare services performance (numbers of patients who attended health services).

State Social Insurance Fund Board of the Republic of Lithuania (SODRA) has records about pensions and social benefits. SODRA's database has been effective since 1994. However it has no data related to health status or diagnosis (<http://www.sodra.lt>).

6. What is the criterion for eligibility for intellectual disability services?

When intellectual disability is suspected in primary care for the first time for children from 0 to 3 years, family physician usually refers child and parents to the early rehabilitation services.

In general there is no specific criterion for eligibility for intellectual disability services. Diagnosis of mental retardation in accordance with ICD-10 could be used for referrals to services within national health system.

7. What type of service provision is currently offered to adults with intellectual disability?

Traditionally, the following three types of services existed in Lithuanian child and adolescent psychiatry during the Soviet period:

- outpatient services -as apart of general psychiatric polyclinics (dispensaries) in larger cities, there has been a district child psychiatrist per 20,000 children;
- inpatient services - there was a tradition to have inpatient units for children with 40 to 60 beds each, in general psychiatric hospitals; the total number of child psychiatric beds was approaching 200 (for about children's population of 1 million); three large institutions for severely and moderately mentally retarded children (under the Ministry of Social Welfare);
- a large network of special schools (more than 40 of them throughout Lithuania), most of them - residential institutions - for children with mild mental retardation (many of these children have been only labeled as mentally retarded, and their real problem was usually social deprivation due to the social problems in families).

All the services for children with psychiatric disorders and mental retardation in the former system were funded by the state budget. The health care budget was responsible for inpatient and outpatient psychiatric services; social welfare provided funds for the psychoneurological institutions for moderately and severely mentally disabled children. The system of education was funding special boarding schools for mildly mentally retarded children.

Currently the health, social, and educational services are undergoing changes in the transitional period to the market economy. In 1997, the Health Insurance Law was introduced, with "per capita" funding for primary health care, and limited pay for outpatient and inpatient services at the secondary and tertiary level. Initially, mental health was not on the list of primary health care services, as it was supposed that general practitioners will be responsible for the whole area of primary health care, including mental health. But psychiatrists, child and adolescent psychiatrists, and NGOs interested in mental health protested against discrimination of mental health services. According to the Mental Health Act, which was adopted by the Lithuanian Parliament in 1995, every municipality has to establish a mental health center - a team of mental health professionals who will provide outpatient mental health care services at the primary level

to the local inhabitants. A psychiatrist, child and adolescent psychiatrist, psychologist, and social worker are included on the list of obligatory team members. At the end of 1997 the Ministry of Health and the Council of Obligatory Health Insurance agreed to introduce amendments to the initial documents, and very limited funding (approximately 0.7 USD for each inhabitant per year) was additionally allocated for the primary mental health care. The process of developing community based mental health centers started, and the main concern of child and adolescent psychiatrists is now to lobby for the autonomy of services for children and adolescents within primary mental health care. The alternate option, rather popular among national and local authorities, is that general psychiatrists could take care of all age groups, including children and adolescents, in the primary mental health care.

One more problem caused by the introduction of Health Insurance was that outpatient services covered by insurance have been restricted to one consultation of any medical specialist once per three months. The philosophy behind this decision was to give priority to the general practitioners, and the medical specialists would only consult the patient when there is a need. In the initial list of specialists, a general psychiatrist was the only representative of mental health professionals. However, after protests from the side of child and adolescent psychiatrists, they were included on the list of medical specialists who would be paid for consultation. But two main problems remain unsolved. The first is how outpatient treatment (e.g., psychotherapy) will be paid. Another problem is that all non-medical professionals (such as, psychologists, speech therapists, clinical social workers) have been excluded from the lists of professionals whose services could be paid by insurance.

According to “National Social Report” done at Ministry of Social Welfare and Labor, 22 stationary social care (long-term) institutions for people with mental disabilities (mixed population with severe mental illness and intellectual disabilities) provided to about 5.3 thousand recipients, including about 30 per cent of them in need of intensive care, were under the jurisdiction of counties in 2004. In 5 municipalities houses of independent living were set for about 100 dwellers with intellectual disabilities. Services at home were provided to 4.4 thousand disabled persons and their families. Day care services for the disabled children and adults were provided by 59 day care (occupational, educational) centres.

3 care institutions under the jurisdiction of counties for children and young persons with intellectual disabilities provided 675 of recipients by the end of 2004, and one municipal institution (The Vilnius Children Pension) cared 57 children.

Additionally the biggest NGO “Viltis” provides following social services (from VILTIS • ANNUAL REPORT • 2004; www.viltis.lt):

During 2004, ambulatory social services (provision of information, consulting, intermediation, social work, social skills training, temporary care, day occupation, assistance at home, transport, etc.) were provided to disabled people in different services and centres. 2 community care home were established and support was provided for the activities of 29 community independent living homes and agencies providing social services. Social services were provided to 2,256 disabled persons. 63 persons were employed under the National Programme for Social Integration of Disabled Persons, of which 7 persons were disabled (4 Category II disabled persons and 3 Category III disabled persons).

Community Care Homes for Mentally Disabled Persons

This project was implemented in 7 institutions and comprised 115 disabled persons. 21 persons were employed under the National Programme for Social Integration of Disabled Persons, of which 2 persons were Category II disabled.

In 2004, the following two community independent living homes and agencies providing social services were established:

- Utena-based Viltis, which permanently houses 35 disabled persons – the premises of 275.7 sq.m. were reconstructed and adapted to the needs of disabled persons. 24 living rooms and 2 recreational and relaxation rooms were equipped in this area;
- Independent Living Home in Jurbarkas attended by 15 disabled persons. During working days, 6 adolescents from the neighbouring villages and the kindergarten Ažuoliukas were brought to this home. Hygienic and self-service skills were taught to disabled persons. They learned to read, to write and to count. For those who did not attend any educational institution before these lessons were the first steps to knowledge.

In 2004, the activities of the following existing community care homes was further maintained and expanded:

- Anykšėiai-based care home Namų Užovėja: the reconstruction of the attics was carried out: 5 rooms were equipped for senior mentally disabled persons who lost their parents or carers;
- Klaipėda Independent Living Home: the environment was cleaned and the premises were adapted to the needs of disabled persons. Accommodation was provided to 8 disabled adolescents in this home;
- Mažeikiai-based independent living home Vilties Erdvė, which accommodates 16 disabled persons: in-house accommodation, catering, daily life, personal hygiene, formation of social skills and legal services were provided in this home;
- Panevėžys-based independent living home Vilties Namai, which accommodates 11 disabled persons: different activities were carried out in this home. Lessons in the woodworker's workshop helped the disabled to acquire work skills. The theatrical activity allowed them to feel and control their body and to strengthen the identity;
- Vilnius-based independent living home Pašilaičiai, which permanently accommodates 9 persons, 6 of which are orphans, and where last year another 5 adolescents spent from several days until several months: transport services were provided using the funds of the programme. Young people could arrive in educational and medical treatment institutions. In addition, they were taught self-help and helped to develop hygienic skills, solidify their knowledge and have a purposeful time.

Provision of Ambulatory Social Services

The project was implemented in 21 institutions and the Šventoji-based psycho-social rehabilitation centre Akimirkos. It comprised 1,813 disabled people. 39 persons were employed under the National Programme for Social Integration of Disabled People, of which 4 Category II and 1 Category III disabled. During the implementation of the project, ambulatory social services indicated in the Catalogue of Social Services were provided to mentally disabled people and their family members: groups for the development of social skills were formed for disabled people who do not attend any educational institution; temporary care for disabled people are ensured in centres and care homes; specialist consultations, information and intermediation services are provided.

In institutions for help to families, particular attention was devoted to work with families and consulting of parents on the disability and integration of their children. Parents were encouraged to form self-help groups and to co-operate with municipal institutions, nearest educational institutions and non-governmental organisations.

The project “Provision of Ambulatory Services” was implemented in the following institutions:

- Alytus family support centre (FSC) (30 disabled persons);
- Alytus district FSC (9 disabled persons);
- Anykščiai FSC (56 disabled persons);
- Elektrėnai FSC (28 disabled persons);
- Ignalina FSC (21 disabled persons);
- Jonava FSC (37 disabled persons);
- Kaunas FSC (40 disabled persons);
- Kėdainiai community social centre (80 disabled persons);
- Klaipėda FSC (20 disabled persons);
- Mažeikiai FSC (114 disabled persons);
- Panevėžys FSC (75 disabled persons);
- Pasvalys FSC (72 disabled persons);
- Plungė FSC (64 disabled persons);
- Radviliškis FSC (146 disabled persons);
- Šiauliai FSC (62 disabled persons);
- Širvinta FSC (42 disabled persons);
- Ukmergė FSC (70 disabled persons);
- Vilkaviškis FSC (50 disabled persons);
- Vilnius Centre of Social Services (300 disabled persons);
- Vilnius public organisation Vilties Akimirka FSC (82 disabled persons);
- Vilnius-based Markučiai day care centre (65 disabled persons);
- Šventoji-based psycho-social rehabilitation centre Akimirkos (350 disabled persons).

Provision of Transport Services

The project comprised 328 disabled persons. Permanent services were provided to 228 disabled persons, one-time services were provided to 100 disabled persons. 3 specialists were employed under the National Programme for Social Integration of Disabled People.

Transport services were provided by:

- Mažeikių Viltis;
- Vilniaus Viltis;
- Vilnius-based public organisation Vilties Akimirka.

Specialised permanent and one-time services were provided to mentally disabled persons in Vilnius and Mažeikiai for the whole year. Specialised permanent services were provided 5 days per week twice a day, whereas one-time services were provided according to individual needs.

8. What sources of income are available for people with intellectual disability?

Now minimum wage is 550 lt (159,4 Euro), but after 1 th of July the minimum wage will be 600 lt (173,9 Euro).